

Self-Reported vs EHR Information Quality; Privacy for Individual and for Family Members

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No Difference in Family Health History as EHR FHH is Self-Reported

<https://familyhistory.hhs.gov/familyhistory.html?action=create>

Your Personal Information

We start the family health history with you. Enter the required personal information and your family members you would like to add to the health history.

* Indicates required information.

*Name:

*Gender: ☐ Male ☐ Female

*Date of Birth:
mm/dd/yyyy

Were you born a twin? ☒ No ☐ Yes - Identical (Same) ☐ Yes - Not Identical

Were you adopted? ☐ Yes

Height Feet Inches -OR-

Weight lbs

Your Health Information

In the list below, select a Disease or Condition (if any)

	Action
Please Select a Disease or Condition	<input type="button" value="1"/>

Your Family Background Information

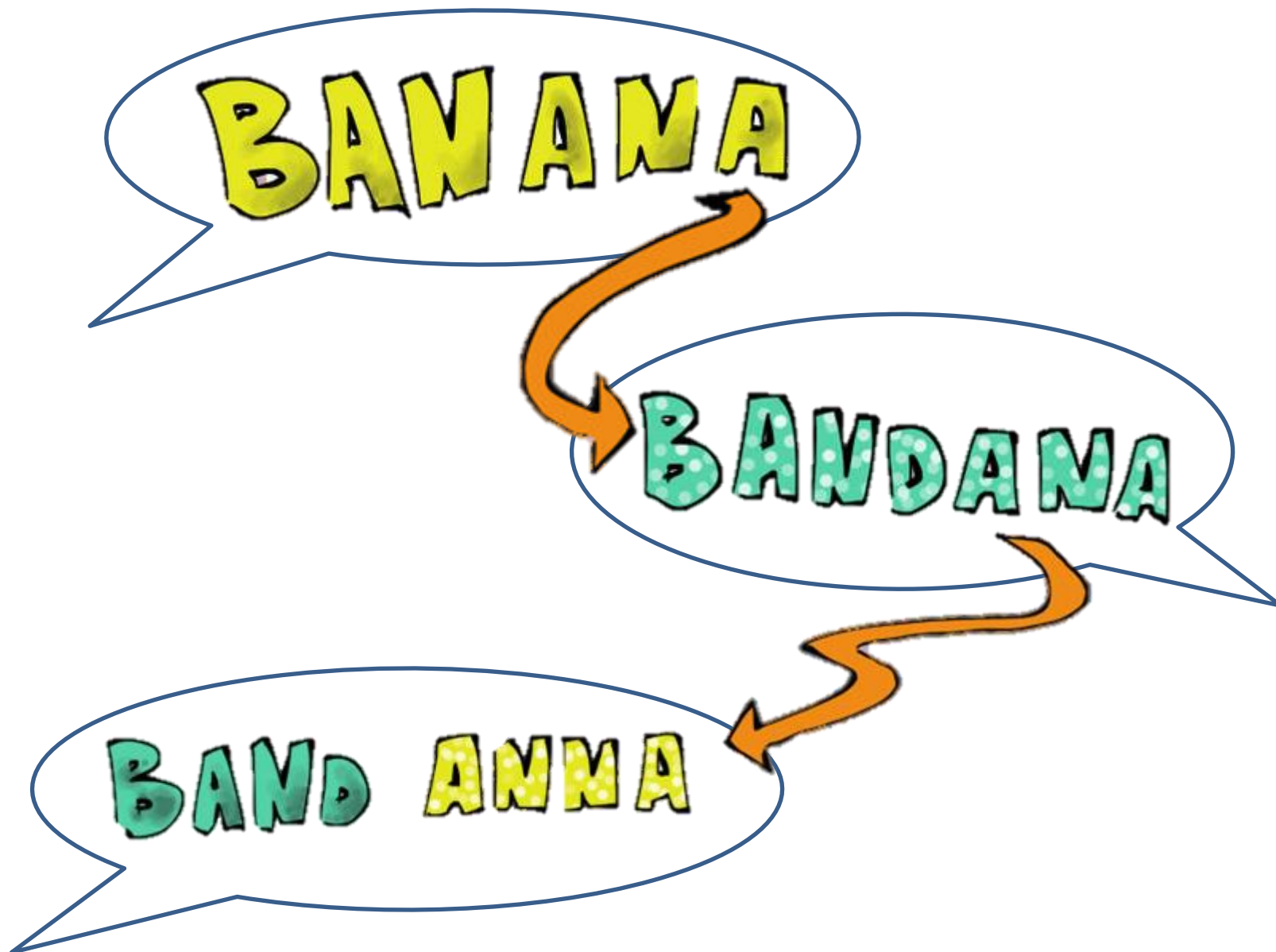
Check here if your parents are related to each other.
Multiple races and ethnicities may be selected.

Race: ☐ White

Ethnicity: ☐ Hispanic

[Why are we asking about Ashkenazi?](#)





We can't expect highly accurate
family medical history if it is
dependent on an individual's
memory

“Garbage in, garbage out”



Your analysis is as good as your data.

Maximize quality of Family Health History

Have Family Members Each Put
in Their Own Information so
that it is Firsthand and
Accurate

... Share

Include as Many Family Members as Possible

Adjust for Missing Family Members

How Does an Individual Collect Good Data?

Patient EHR Data

In EHRs, Physician Exam
and Labs are only Objective
data

Import Physician Exam Notes and Labs data

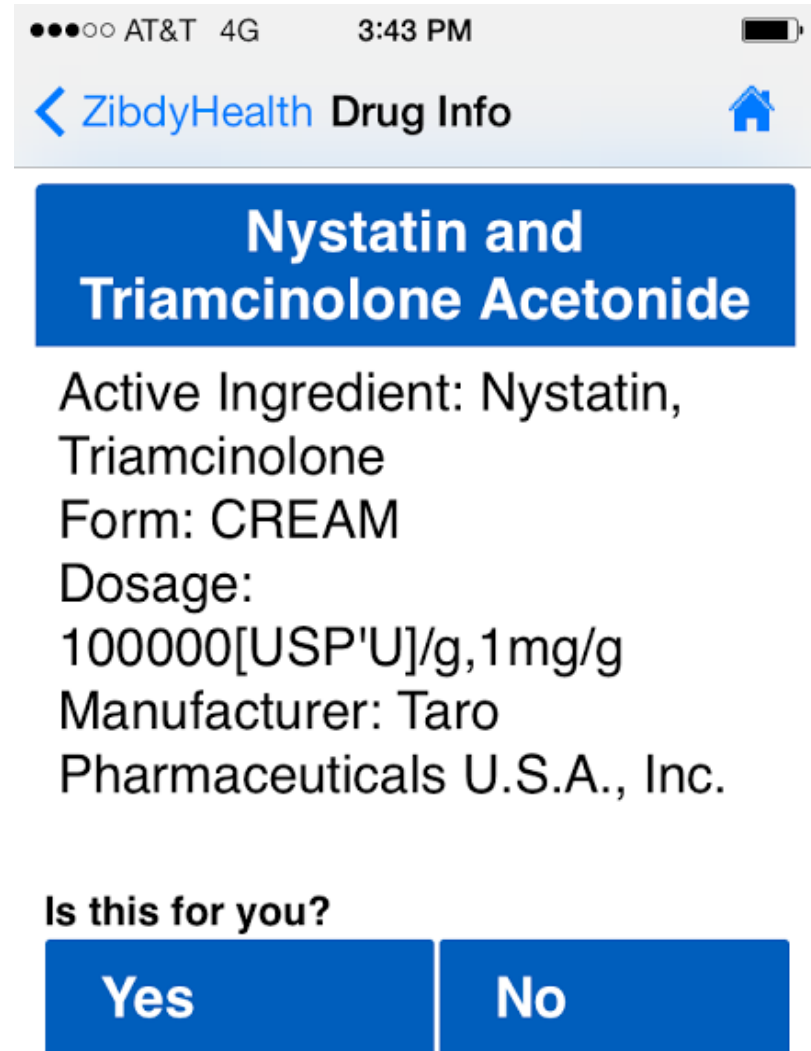
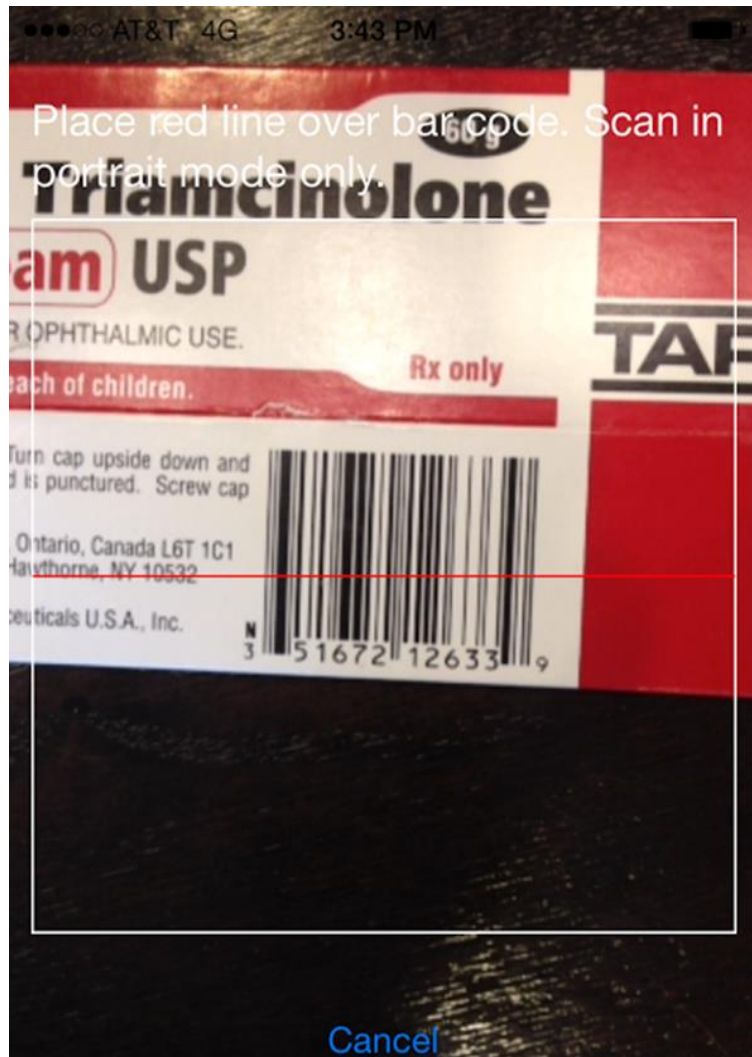
“Smart HIE” - Transfer Data Ownership and Makes Data Useful

User Entered Data

Unstructured to Structured Data

Scanning Medication List

Simple as 1-2-3



Fran Tribiani



Conditions / Illnesses

Family Medical History

Indications for 1st Degree

Relations

Medication

Breast Cancer

Cyclophosphamide

Diabetes Mellitus Type 2

Byetta

Sore Throat

Childrens TYLENOL

Back Pain

IBUPROFEN Children's
(ibuprofen) suspension

Prostate Cancer

Taxotere

Cancer (high calcium levels
in)

Dexameth

Others: Dry Eye

REFRESH TEARS

Skin Fungal Infection

Nystatin and Triamcinolone
Acetonide

Indications for 2nd Degree

Relations

Medication

Breast Cancer

Gemzar

Breast Cancer

Cyclophosphamide

Will People Use an Application if
the Benefits are Many Years
Out?

Or Someone Else Benefits?

Toothbrush Test

Use => Data => Share

Privacy and Sharing Data


Default Should be Set to
“NO” Sharing

Let Patient Control Sharing Preferences

Section and Item Level Privacy

Permissions and Privacy

iPad 9:33 PM 53%

[Select Permissions](#) Change Permissions 

Permissions allowed for Nurse Jaqui

	Add	View	Delete	Modify
Personal Info	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allergies	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medications	<input type="checkbox"/>	<input checked="" type="checkbox"/>		<input type="checkbox"/>
Medical History	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vaccines	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Labs	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reminders	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
Vitals	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		
Permissions		<input type="checkbox"/>		<input type="checkbox"/>
Notes	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		

Save

Patient controls permission through simple check-box

Conclusions

- Distributed data collection via “Family-sourcing” leads to collection and maintenance of **Accurate Family Health History**
- Giving patient control of their data allows them to determine access level to their data and making it easy for them to use your analytic tools for FHH



Accurate Data Collection and Privacy for Family Health Histories

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